

## H.B.369, AN ACT CONCERNING AUTHORIZATION FOR THE USE OF FEEDING TUBES AND ANTIEPILEPTIC MEDICATIONS IN SCHOOL SETTINGS.

I, Jill Isenberg, mother and Educator for the Connecticut Early Intervention System, have had the pleasure of being one of a handful of people whom Alyssa Temkin has chosen as a safe adult to care for her medical needs. This process of rapport building with Alyssa occurred as both Alyssa and my daughter and Gayle and I became friendly. We spent a lot of time together during the days our children were in preschool hanging out in the hallways watching the clock and waiting for alarms to ring to remind Gayle to get ready for Alyssa's feedings. I was able to see firsthand the intensity of the strict feeding regimen. In addition, we spent time together outside of preschool during child-centered activities and learning opportunities. During these play occurrences we mutually accepted one another with open arms. I personally remember clearly the first time I peeked into the girls' classroom only to find my daughter sitting in between Alyssa and her mom while Gayle explained the entire process. I learned so much about Alyssa from Gayle and by Alyssa herself letting me into her personal space/ boundaries. When Alyssa began requesting me to feed her I was thrilled to be able to accept her request! I can't overstate the importance of caregivers having ample opportunities to live, eat, and breathe the Temkin's life. The only people in this world who can provide this one on one training/ experience/expertise are the Temkin's , the medical providers, and those trained by the Temkin's and medical professionals to best provide Alyssa's GSD care. If and when Alyssa is comfortable she will let us know. Alyssa is a very bright little girl who has the right to be given age appropriate choices/ decisions over her body. If this comfort level has been established all parties involved will be benefitted in many ways. The Temkin's may even have respite time to look forward too and be willing to step aside and allow others to take over in Alyssa's care.

I have had the honor to be a friend who has been fortunate to enough to be a part of the Temkin's life in such a way where they believe a smooth transition could take place as Alyssa and I continue to establish rapport with one another in her natural environment. It's clearly not about the medical background of individuals but the comfort level of the family and child and most importantly providing family centered services with the passion involved in keeping Alyssa safe and stable at all times!